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Assessing Shared Decision-Making in Cystic Fibrosis Care Using collaboRATE: A Cross-Sectional Study of 159 Programs

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Abstract

There are numerous opportunities for shared decision-making (SDM) in cystic fibrosis (CF) care, yet little is known about patients' SDM experiences. This study evaluated SDM across 159 CF care programs (4024 participants) in the United States. Shared decision-making was assessed using the patient-reported **collabo**RATE measure, which was included in the CF Foundation's Patient and Family Experience of Care Survey over 18 months. Overall, 69% of respondents reported experiencing SDM. Respondents at pediatric programs were more likely to experience SDM than those at adult programs (72% vs 67%, $P < .001$). Multivariable logistic regression analyses showed a relationship between SDM and patient age, whereby SDM was less likely to occur with patients aged 18 to 24 years, compared to some younger and older age groups ($P = .02$-$<.001$). Shared decision-making was more likely to occur at pediatric programs when patients had better general health ($P = .02$-$<.01$), and at pediatric and adult programs when patients had better mental health ($P = .02$-$<.001$). Disparities in SDM experiences highlight a need to improve decision-making processes in CF care. Interventions tailored for improving SDM among specific patient populations may be particularly advantageous.

Keywords

shared decision-making, communication, cystic fibrosis, chronic care, patient experience

Introduction

Shared decision-making (SDM) is a process where patients and clinicians share information and make care decisions together (1). Cystic fibrosis (CF) provides numerous SDM opportunities, since it is a complex genetic, multi-organ lifetime disease (2) with emerging new therapies (3). People with CF are typically seen 4 or more times a year by a multidisciplinary care team and engagement of SDM at each visit may best ensure that treatment decisions and care plans meet the personal needs and goals of patients with CF. Evaluating decision-making experiences among patients with CF and their families would help CF clinical teams determine whether and where improvement is needed.

A brief, patient-reported measure of SDM, "**collabo**RATE," was developed by Elwyn et al (4) and has been endorsed by the National Quality Forum. Studies using **collabo**RATE have shown associations between **collabo**RATE scores and some patient characteristics (5–8), suggesting there is variation in patients' experiences of SDM. For instance, higher rates of SDM have been associated with increasing age (5–9), female gender (5,6,8,9), and better general and mental health (6).

In CF care, the SDM experience is largely unknown, including whether SDM varies relative to patient or program characteristics. The CF Foundation accredits CF programs across the United States to ensure that people with CF have access to high-quality, specialized care. For teams to receive feedback from patients and families, the CF Foundation supported the national Patient and Family Experience of Care

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Survey (PFEC) (10), and in 2018, the survey introduced **collabo**RATE. Utilizing **collabo**RATE responses, the aims of this study were to explore overall rates of SDM in CF care, whether SDM was associated with patient characteristics, and how SDM varied across CF programs.

Method

Design and Setting

This is a cross-sectional secondary research study that utilized existing data collected from the PFEC, a quality improvement activity (informed consent was optional and not required). The PFEC was voluntarily implemented at 170 accredited CF programs (located at teaching and community hospitals) across the United States. There were 3 types of CF programs: (1) Pediatric programs providing care to patients younger than 18 years and some adults, (2) Adult programs providing care to adults, and (3) Affiliate programs providing care to patients of any age in underserved areas. The CF Foundation commissioned a third-party survey vendor, Quality Data Management Inc. (QDM), to manage the PFEC data collection. This study utilized PFEC data captured between July 2018 and December 2019.

Data Collection

The survey vendor worked with CF programs to obtain each patient's contact information and clinic visit dates. Patients became eligible for a survey invitation after a clinic visit, and no more than twice a year. Eligible adults with CF completed an adult survey and parents (or caregiver) of a child with CF completed a pediatric survey. Both pediatric and adult surveys had the same questions with the inclusion of "your child" in some pediatric questions (see Supplementary File 1).

Respondents completed PFEC in one of 3 ways: online at home, telephone at home, or tablet computer in the clinic. For online and telephone at home, an invitation to voluntarily complete a survey was sent by email, if available, or by post. The invitation contained the survey URL and telephone number to complete the survey by personal telephone interview or speech recognition system. Up to 3 reminder telephone calls were made to nonresponders and they were placed on a recontact list (survey sent again after a clinic visit in 4 months or later) if they had not completed a survey within 30 days. In rare instances, a respondent completed the survey more than twice per year, if they completed both an initial and recontact survey. For programs that chose to deliver the survey via tablet in the clinic, a clinic staff member asked the patient or family member to complete the survey toward the end of their visit (see Supplementary File 2 for detailed protocol).

Measures

The PFEC had 28 questions in total (23 closed-ended, 5 open-ended). Of these, the CF Foundation developed 19 questions and 9 were preexisting measures. Additional clinic-reported variables were also merged with PFEC data, to provide additional information about patients and their clinic.

This study focuses on **collabo**RATE, a brief 3-item patient-reported experience measure of SDM (4). **collabo**RATE was developed based on core elements of SDM and consultation with end users and assesses experiences of SDM across 3 domains: explanation of health issues, elicitation of patient preferences, and integration of patient preferences. Each item has a 10-point response scale ranging from 0 "No effort was made" to 9 "Every effort was made." **collabo**RATE has previously undergone psychometric testing, demonstrating discriminative and concurrent validity, sensitivity to change, and intrarater reliability (11). The adapted version of **collabo**RATE for parents and guardians has also undergone psychometric testing, demonstrating convergent and divergent validity, and test–retest reliability (12).

Other patient/caregiver-reported variables utilized for this study included patients' years of relationship with their clinic, assessed via a single self-developed item with response options of "Less than 2 years," "2 to 5 years", or "Greater than 5 years." Patients' general ("overall") health status and mental ("mental or emotional") health status were both assessed via single item measures adopted from the Hospital Consumer Assessment of Healthcare Providers and Systems survey (13). Both items had response options of "Excellent," "Very good," "Good," "Fair," and "Poor." The CF programs reported their program type and patients' age-group and gender (see Supplementary File 1 for all measures).

Statistical Analysis

The analysis only included respondents who completed all 3 **collabo**RATE items. We used a "top-score" method for **collabo**RATE by calculating the proportion of respondents who reported a top (best) score of "9" for all 3 items, which we considered as having 'experienced SDM'. This scoring method was previously validated (11,12) and chosen for this study a priori due to its high standard of assessment and ability to overcome ceiling effects, often seen in patient experience measures. Respondents with missing data on other variables were only excluded from analyses that included those variables. The analysis excluded 11 affiliate programs, since the majority had small patient volumes.

For study aim 1, chi-square analyses compared the overall percentage of **collabo**RATE top scores across program types and survey completion modes. For aim 2, univariable and multivariable logistic regression analyses described associations between **collabo**RATE and patient characteristics for

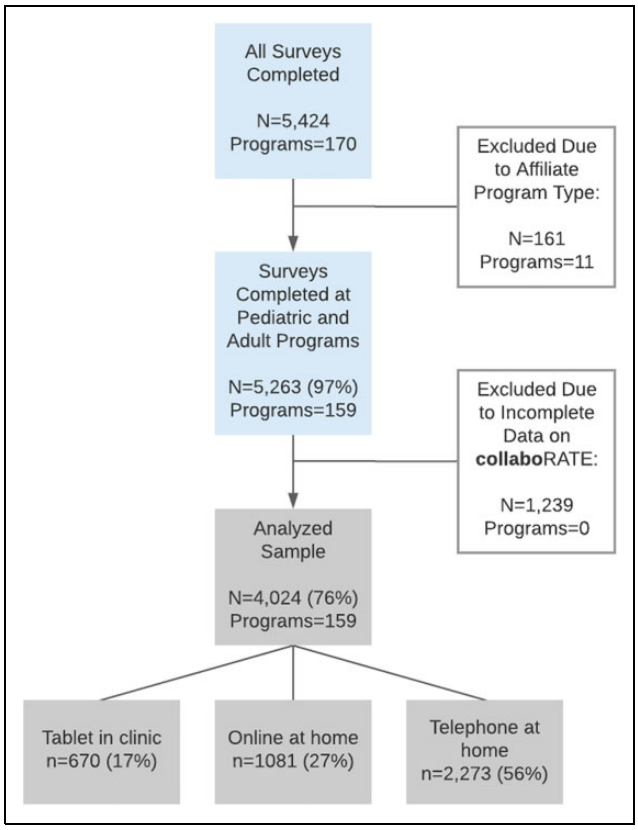

Figure 1. Participant flowchart.

pediatric and adult programs, separately. The analysis excluded respondents 25 years and older attending pediatric programs due to the small number of respondents. Additionally, due to the small number of respondents selecting "poor" for both general and mental health status measures, the analysis grouped response options of "fair" and "poor." Nominal statistical significance was set at $P < .05$ for all analyses. For aim 3, program-level analyses excluded programs with less than 25 respondents, to reduce potential uncertainty associated with small samples (14). The 95% CI for each program's **collabo**RATE top score rate was compared to the overall rate for pediatric and adult programs, separately.

Two sensitivity analyses were conducted for the multivariable models. First, with respondents' first or only survey with complete data on **collabo**RATE, to identify whether including more than one survey from some respondents substantially affected the results. Second, by respondent's survey completion mode, to identify potential differential mode effects. Lastly, the transition to adulthood is a critical time with an increasing focus in CF care because of improved survival (15). Thus, a multivariable model assessed factors associated with SDM for the subgroup of respondents aged 18 to 24. Due to the small number of adult respondents at pediatric programs, instead of running 2 separate models, program type was included as a predictor.

Results

Characteristics of Respondents

There were a total of 5263 surveys completed at pediatric and adult CF programs. Of these, 4024 surveys (76%) had complete data on **collabo**RATE from 159 CF programs (see Figure 1). Table 1 describes respondents' characteristics by program type. For both pediatric and adult programs, patient gender had an equal distribution; however, differences were seen across program types for years of relationship with program, general health, and mental health.

Compared to national CF Foundation Patient Registry (CFFPR) data for 2019 (16), the study sample as a whole was representative of gender, but underrepresented patients 18 years and over (52.4% vs 56.0%, $P < .001$). CF Foundation Patient Registry data were not available for direct comparisons of other characteristics in the PFEC. However, adults in the CFFPR had higher rates of screening positive for anxiety disorder and depression, than those aged 12 to <18 years (24% vs 5% and 28% vs 4%, respectively), which mirrors trends in self-reported mental health in the PFEC study sample.

Overall collaboRATE Scores

Sixty-nine percent (n = 2794) of all respondents reported a **collabo**RATE top score. Respondents at pediatric programs were significantly more likely to report a **collabo**RATE top score (72%, 87 programs) than respondents at adult programs (67%, 72 programs; $\chi^2 = 11.80$, $P < .001$). Respondents completing the survey via tablet in the clinic were significantly more likely to report a **collabo**RATE top score (75%) than those completing the survey online at home (66%; $\chi^2 = 14.68$, $P < .001$) or via telephone at home (69%; $\chi^2 = 8.58$, $P = .003$).

Association of collaboRATE Scores With Patient Characteristics, by Program Type

Table 2 details result from the univariable and multivariable logistic regression analyses. For the pediatric programs, there were significant univariable associations with **collabo**RATE top scores for age, general health status, and mental health status. For the multivariable model, these characteristics all remained significant predictors; however, the strength and number of associations were attenuated. Pediatric program respondents with a child aged between 11 and 17 years (odds ratio [OR]: 1.7, CI: 1.1-2.6) were more likely to report a **collabo**RATE top score than respondents aged 18 to 24 years. Respondents who rated general health as excellent (OR: 2.3, CI: 1.4-4.0) or very good (OR: 1.8, CI: 1.1-3.0) were more likely to have a **collabo**RATE top score, than those rating general health as fair or poor. Respondents who rated mental health as excellent (OR: 2.6, CI: 1.6-4.2) or very good (OR: 2.0, CI: 1.3-3.1) were more likely to have

Table 1. Characteristics of Respondents Who Completed **collabo**RATE, by Program Type.

Characteristic	Pediatric programs n = 2091 n (%)	Pediatric programs n = 2091 (95% CI)	Adult programs n = 1933 n (%)	Adult programs n = 1933 95% CI	All programs n = 4024 n (%)
Age (years) (n = 4024)[a]					
Under 2	217 (10)	-			217 (5)
2-5	421 (20)	-			421 (10)
6-10	525 (25)	-			525 (13)
11-17	753 (36)	-			753 (19)
18-24	146 (7)	-	311 (16)	-	457 (11)
25-34	17 (1)	-	660 (34)	-	677 (17)
35-44	5 (<1)	-	433 (22)	-	438 (11)
45-64	4 (<1)	-	449 (23)	-	453 (11)
65 plus	3 (<1)	-	80 (4)	-	83 (2)
Gender (n = 4024)					
Male	1053 (50)	(48.2-52.5)	973 (50)	(48.1-52.6)	2026 (50)
Female	1038 (50)	(47.5-51.8)	960 (50)	(47.4-51.9)	1998 (50)
Length of relationship (n = 3984)					
Less than 2 years	332 (16)	(14.4-17.5)	263 (14)	(12.3-15.4)	595 (15)
2 to 5 years	475 (23)	(21.0-24.6)	391 (21)	(18.7-22.4)	866 (22)
Greater than 5 years[b]	1273 (61)	(59.1-63.3)	1250 (66)	(63.5-67.8)	2523 (63)
General health status (n = 3099)					
Excellent[b]	499 (31)	(28.9-33.4)	212 (14)	(12.4-15.9)	711 (23)
Very good[b]	635 (40)	(37.3-42.1)	425 (28)	(26.1-30.7)	1060 (34)
Good[b]	363 (23)	(20.6-24.7)	559 (37)	(34.9-39.8)	922 (30)
Fair[b]	86 (5)	(4.3-6.5)	247 (16)	(14.6-18.4)	333 (11)
Poor[b]	18 (1)	(0.6-1.6)	55 (4)	(2.7-4.6)	73 (2)
Mental health status (n = 3174)					
Excellent[b]	601 (37)	(34.8-39.5)	398 (26)	(23.4-27.7)	999 (31)
Very good	516 (32)	(29.6-34.2)	430 (28)	(25.4-29.9)	946 (30)
Good[b]	362 (22)	(20.3-24.4)	497 (32)	(29.6-34.3)	859 (27)
Fair[b]	118 (7)	(6.0-8.6)	204 (13)	(11.4-14.8)	322 (10)
Poor	21 (1)	(0.7-1.8)	27 (2)	(1.1-2.4)	48 (2)

[a]95% CIs not presented for age groups as comparisons were deemed unnecessary due to program type inclusion being largely age-dependent.
[b]Significant difference across program type.

a **collabo**RATE top score, than those rating mental health as fair or poor.

For the adult programs, there were significant univariable associations with **collabo**RATE top scores for age, length of relationship, general health status, and mental health status. For the multivariable model, age and mental health status remained significant predictors; however, the strength and number of these associations were attenuated. Respondents aged 35 to 44 years (OR: 1.7, CI: 1.2-2.5) or 45 to 64 years (OR: 2.0, CI: 1.3-2.9) were more likely to report a **collabo**RATE top score, than respondents aged 18 to 24 years. Respondents who rated their mental health as excellent (OR: 2.1, CI: 1.4-3.2) or very good (OR: 1.6, CI: 1.1-2.3) were more likely to report a **collabo**RATE top score, than those who rated it fair or poor.

collaboRATE Variation by Individual Program

There were 35 pediatric programs (n = 1559) and 25 adult programs (n = 1329) with 25 or more survey responses. Compared to the **collabo**RATE top score rate across all 35 pediatric programs (72%), 2 pediatric programs had lower rates (44%, CI: 26%-63% and 60%, CI: 49%-70%) and 3 pediatric programs had higher rates (82%, CI: 75%-89%; 85%, CI: 76%-94%; and 86%, CI: 76%-96%; Figure 2A). Compared to the **collabo**RATE top score rate across all 25 adult programs (67%), 2 adult programs had lower rates (52%, CI: 38%-67% and 54%, CI: 40%-67%) and 4 adult programs had higher rates (79%, CI: 71%-86%; 80%, CI: 68%-92%; 82%, CI: 69%-94%; and 84%, CI: 74%-93%; Figure 2B).

Sensitivity and Subgroup Analyses

The analysis of respondents' first or only survey showed minor differences to the main multivariable models and these pertained to patients' age and general health (see Supplementary File 3). The analyses by survey completion mode revealed some significant associations consistent with the main multivariable models pertaining to age, and mental and general health, for surveys completed via telephone and online at

Table 2. Univariable and Multivariable Logistic Regression Analyses: Association of **collabo**RATE Top Score (%) and Patient Characteristics, by Program Type.

	Univariable						Multivariable					
	Pediatric programs (n = 2062)			Adult programs (n = 1933)			Pediatric programs (n = 1453)			Adult programs (n = 1385)		
Characteristic	OR (95% CI)	*P*	top score %	OR (95% CI)	*P*	top score %	OR (95% CI)	*P*	top score %	OR (95% CI)	*P*	top score %
Age (years)												
Under 2	2.10 (1.33-3.3)	<.01	76				1.48 (0.73-3.01)	.28	74			
2-5	1.85 (1.25-2.74)	<.01	73				1.55 (0.89-2.70)	.12	76			
6-10	1.62 (1.11-2.37)	.01	70				1.40 (0.89-2.20)	.15	70			
11-17	1.93 (1.33-2.79)	<.01[a]	74				1.67 (1.08-2.57)	.02	71			
18-24 (ref)			60			57			59			56
25-34				1.56 (1.18-2.05)	<.01	67				1.33 (0.94-1.89)	.11	64
35-44				1.73 (1.28-2.34)	<.01[a]	69				1.69 (1.15-2.48)	<.01	70
45-64				1.86 (1.38-2.52)	<.01[a]	71				1.98 (1.35-2.91)	<.01[a]	72
65 or older				1.79 (1.06-3.04)	.03	70				1.88 (0.96-3.68)	.07	71
Gender												
Male	1.02 (0.84-1.23)	.86	72	0.99 (0.82-1.19)	.90	67	0.98 (0.78-1.24)	.87	71	0.85 (0.67-1.07)	.17	66
Female (ref)			72			67			71			67
	(n = 2051)			(n = 1904)								
Length of relationship												
<2 years (ref)			74			61			72			61
2-5 years	0.97 (0.7-1.33)	.84	73	1.07 (0.78-1.47)	.69	62	1.15 (0.68-1.95)	.61	75	1.00 (0.67-1.47)	.98	63
>5 years	0.88 (0.67-1.16)	.37	71	1.45 (1.10-1.91)	<.01	69	1.04 (0.64-1.69)	.88	70	1.20 (0.85-1.69)	.31	69
	(n = 1578)			(n = 1498)								
General health status												
Excellent	3.74 (2.37-5.9)	<.01[a]	81	1.6 (1.09-2.35)	.02	74	2.33 (1.36-3.98)	<.01	80	1.30 (0.82-2.06)	.26	73
Very good	2.45 (1.59-3.78)	<.01[a]	73	1.27 (0.93-1.74)	.13	69	1.83 (1.11-3.01)	.02	72	1.11 (0.77-1.58)	.58	69
Good	1.54 (0.98-2.42)	.06	64	1.06 (0.79-1.42)	.69	65	1.36 (0.83-2.24)	.22	64	1.04 (0.76-1.42)	.81	65
Fair or poor (ref)			53			64			50			63
	(n = 1592)			(n = 1556)								
Mental health status												
Excellent	3.31 (2.24-4.89)	<.01[a]	79	2.33 (1.65-3.29)	<.01[a]	76	2.63 (1.63-4.24)	<.01[a]	80	2.11 (1.40-3.19)	<.01[a]	75
Very good	2.33 (1.58-3.43)	<.01[a]	72	1.71 (1.23-2.39)	<.01	70	1.99 (1.27-3.11)	<.01	73	1.55 (1.07-2.26)	.02	69
Good	1.71 (1.14-2.55)	<.01	65	1.19 (0.87-1.64)	.28	61	1.51 (0.96-2.35)	.07	62	1.18 (0.84-1.68)	.34	62
Fair or poor (ref)			53			57			51			57

Abbreviations: OR, odds ratio; ref, reference group.
[a] $P < .001$.

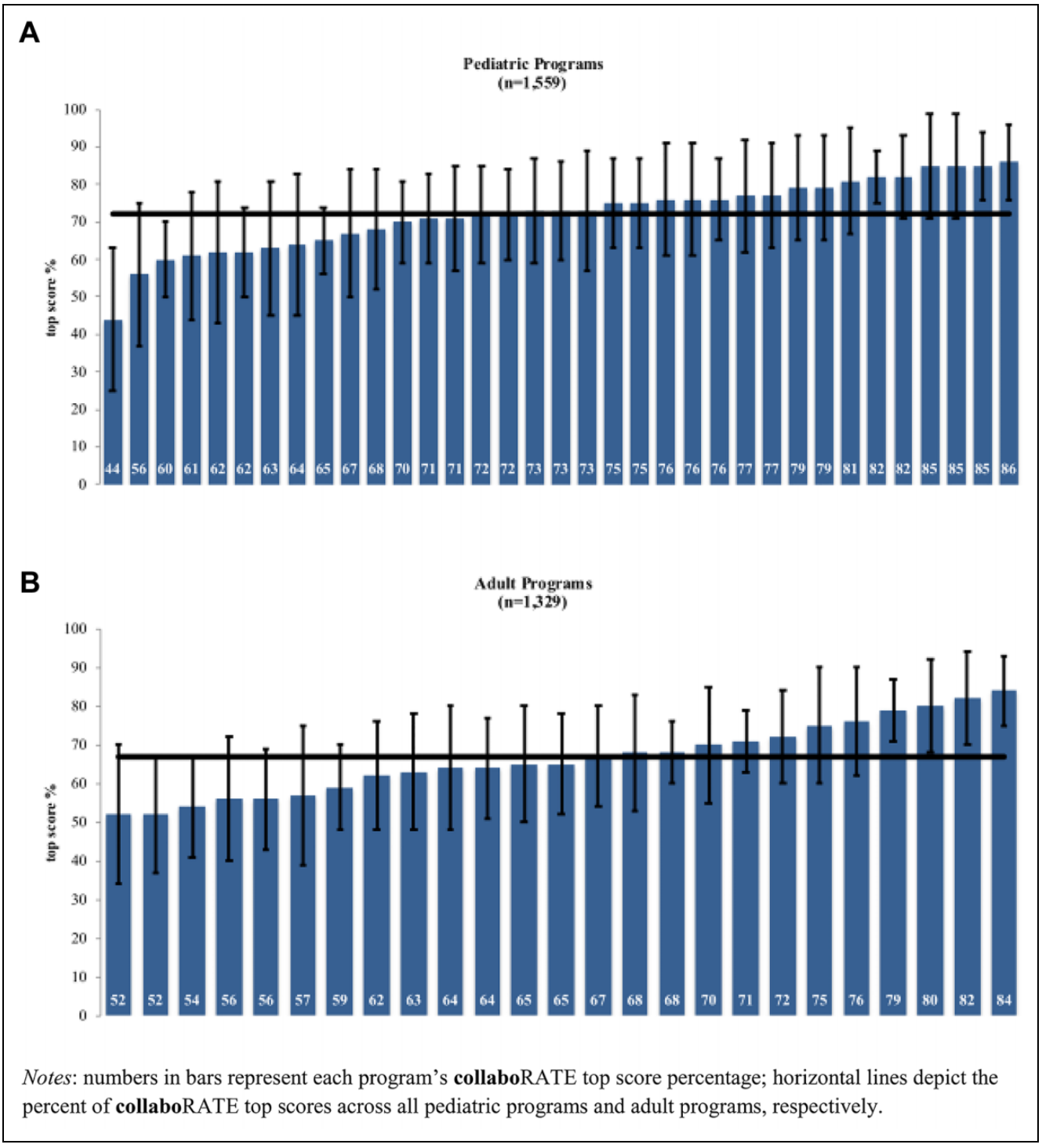

Figure 2. collaboRATE top score rates (with 95% CIs) for programs with 25 or more respondents.

home. Age was also a stronger predictor in the telephone completion group and there were no significant associations in the tablet completion group (see Supplementary File 4).

The subgroup analysis of 18- to 24-year-old respondents showed that those with a length of relationship of 2 to 5 years (OR: 2.1, CI: 1.1-4.1) were more likely to report a **collabo**RATE top score, than those with a relationship of less than 2 years. Respondents who rated their general health as good (OR: 0.44, CI: 0.19-1.00) were less likely to report a **collabo**RATE top score, than those who rated it fair or poor.

Respondents who rated their mental health as excellent (OR: 3.4, CI: 1.5-7.9), very good (OR: 3.8, CI: 1.8-8.1), or good (OR: 2.3, CI: 1.1-4.8) were more likely to report a **collabo**RATE top score, than those who rated it fair or poor (see Supplementary File 5).

Discussion

Key Findings

In this study, we sought to identify the overall and program-level experience of SDM in CF care, as well as whether patient characteristics were associated with higher or lower rates of SDM. We found variation in SDM experiences across individual CF programs, program types, survey completion mode, and that patient characteristics were associated with SDM. At both pediatric and adult programs, there were lower rates of SDM among respondents reporting fair or poor mental health, compared to those reporting better mental health. A similar pattern occurred for general health at pediatric programs. At both pediatric and adult programs, there were lower rates of SDM among respondents aged 18 to 24 years, than in some other age groups. Among the subgroup of respondents aged 18 to 24 years specifcally, there were also associations between SDM and length of relationship, general health, and mental health.

Context and Implications

This is the first study to conduct a large-scale examination of **collabo**RATE in a chronic care population through the use of a routine experience of care survey. The variation we saw across CF programs was consistent with prior research in primary and specialty care settings (14) and suggests that a collaborative network approach between higher and lower performers may improve overall SDM practice patterns in CF care (17). For the adult programs', the higher rates of **collabo**RATE top scores seen with increasing patient age and better mental health status are in line with patterns in **collabo**RATE scores seen in other primary and specialty care adult populations (5,6,9). We did not, however, identify a similar effect of general health (6) or gender (5,6,9).

Despite a tendency for people in this study reporting more health burden to also report poorer SDM experiences, it is perhaps most critical for this population to experience SDM. In CF care, patients with more health burden may be in the midst of acute health crises that spur changes to their existing care plans. Shared decision-making is a powerful process for ensuring that these often complex plans continue to fit the resources and constraints each individual and family brings to self-management, which is undertaken primarily outside the health care context (18,19). A clinic coordinator or other team members could be leveraged as an additional resource for patients and families, to better facilitate SDM.

The disparity we observed in **collabo**RATE top scores between respondents aged 18 to 24 and their counterparts in different age groups is worthy of further study. This group is in transition from pediatric care, where there is substantial involvement and support from parents and family members, to more independently managing clinical interactions and care plans. Patients in this age-group are also often in the process of developing relationships with new clinical teams. Trust between patients and clinicians develops over time and has been identified as key to SDM (20,21). These factors may have contributed to the higher rate of **collabo**RATE top scores among 18- to 24-year-old's with a clinical relationship of 2 to 5 years, compared to shorter than 2 years; although this improvement did not persist for relationships greater than 5 years. Also among this subgroup, the finding of lower top score rates for those reporting good general health compared to fair/poor is of opposing trend to the main study findings and is not evident for those reporting excellent or very good general health. Although there is no clear explanation for this, the smaller sample and near threshold *P* value suggest further investigation may be warranted to substantiate this finding.

Preparing adolescents for in-depth participation in health care service through the use of developmentally appropriate SDM interventions tailored for pediatric practice, is a promising approach to encouraging SDM in this population (22) and could serve as a foundation for optimal decision-making experiences throughout the transition to adulthood. However, a current lack of SDM interventions tailored for use by adolescents with CF is a barrier (23). To effectively bridge this gap, future research should explore the decision support needs of adolescents and young adults with CF, and then work with patients and CF teams to develop SDM interventions that respond to these needs.

Lastly, for the large majority of pediatric program patients (those <18 years), PFEC items were modified for parent/caregivers as proxy reporters. Considering research indicating that adolescents' with CF respond more positively to health-related measures than their parents (24), there may be benefits in further exploring the impact of parent/caregiver versus self-completion of patient experience and health-related measures, among adolescents with CF.

Strengths and Limitations

The PFEC is the most comprehensive source of experience data for people with CF and their families in the United States. However, it is voluntary for CF programs to implement the survey and for patients and families to complete it. Although our sample was representative of gender, the lack of available data on other patient characteristics (eg, race, ethnicity, education) means we cannot estimate the extent to which it is representative of the broader population of people with CF in the United States. Further, given the possible range in time post-visit for PFEC completion, recall bias is a possibility. Our overall survey mode comparison suggests that those completing the survey at the time of their visit are more likely to report SDM, although this finding could also be attributed to the specific programs that chose to implement in-clinic

completion or potential differences in patient populations. Finally, while we prioritized comparisons by program type to better inform practice, a limitation of this study is combining the 2 respondent groups (patient and proxy) for pediatric programs. Our analyses also did not account for varied care delivery systems (eg, community vs teaching hospitals) that may impact the experience of care.

Conclusion

This large-scale study of patients' and families' CF care experiences contributes a novel look at SDM trends in routine chronic care. Disparities in the experience of SDM highlight a need to improve CF decision-making, especially for adolescents transitioning to adult CF care and for people experiencing a mental health burden. The CF Foundation is well positioned to support the enhancement of SDM experiences and to further investigate the variation observed across CF programs.

Authors' Note

Karen Homa and Gabrielle Stevens are Joint lead authors. This study was approved for secondary research purposes by the Dartmouth Committee for the Protection of Human Subjects (#31976). All procedures in this study were conducted in accordance with Dartmouth College Committee for the Protection of Human Subjects approved protocols. The PFEC itself is considered a quality improvement activity, thus, obtaining informed consent was optional under the HIPAA Privacy Rule for all covered entities (i.e., participating CF programs). We are not aware of how many CF programs chose to do this. The use of PFEC data for this study was considered secondary research for which consent was not required.

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Declaration of Conflicting Interests

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Supplemental Material

Supplemental material for this article is available online.

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